Early Identification for Health and Development

The early years of a child's life are critical for healthy development into adulthood. All children, including those with Attention-deficit/hyperactivity disorder (ADHD), fragile X syndrome, hearing loss, muscular dystrophy, spina bifida, and Tourette Syndrome, can achieve improved quality of life, experience independence and expect to reach their full potential if the physical and mental health needs are met throughout the lifespan.

Unfortunately, many children living with complex disabling conditions, hearing loss, or mental, emotional or behavioral conditions experience poor health and do not do well in school. Many children are not screened or diagnosed early in childhood, and do not receive needed services or medical care at the time in his or her life when they could have their greatest impact. Even when children are identified early, families face many challenges such as accessing health care services, inadequate medical care, and loss of care by medical specialists as their children grow into adulthood.

NCBDDD's Division of Human Development and Disability and its partners are dedicated to early identification, intervention, and treatment for children with complex disabling conditions, hearing loss, or mental, emotional or behavioral conditions. Our work can improve their mental and physical health, development, communication skills and social inclusion. These children can be active participants in their neighborhoods and achieve in school; and as adults, they can live, work, and contribute to their communities. Accessible and effective services during childhood ensure this path to success.

2012 Accomplishments

- Completed data collection of the *Project to Learn about ADHD in Youth (PLAY)*, one of the largest community-based epidemiological studies on ADHD. Recently published the study's first estimates of community-based ADHD prevalence and medication treatment. The National Resource Center on ADHD provided much needed science-based information and programs on ADHD to over 1 million people as of September 2012.

- Led efforts in public health-oriented electronic health data through three early hearing loss detection and intervention (EHDI) activities: Centers for Medicare and Medicaid Services adoption of EHDI electronic health record measure as one of 29 measures for eligible hospitals to qualify for their Electronic Health Record (EHR) incentive program; enhanced data collection through technical and capacity-building assistance to 52 states and territories; and, successful demonstration of the electronic exchange of hearing screening results and patient demographics between clinical EHRs and public health entities.

2012 Accomplishments (continued)

- Published the first study indicating higher number of people may have a premutation of the fragile X gene than previously thought, placing them at risk for fragile X-associated disorders even if they don't have fragile X syndrome itself. Symptoms of fragile X-associated disorders can include early menopause, or tremors similar to Parkinson's disease.

- Published evidence showing that preschool-aged children whose mothers participated in the Legacy for Children™ study had fewer clinically significant behavioral problems. Completed the first year of Early Head Start feasibility testing for the Legacy for Children™ positive parenting program across four states.

- Funded and developed with its partners a new web-based tool, www.childmuscleweakness.org, that helps primary care clinicians, physical and occupational therapists, and other specialists identify and evaluate child muscle weakness, including muscular dystrophy. Key components of the tool have been endorsed by the American Academy of Pediatrics.

Rachel's Story

Rachel is the mother of three children with fragile X syndrome and ADHD.

To read Rachel's story, visit: www.cdc.gov/NCBDDD/fxs/stories.html

- The National Spina Bifida Patient Registry was expanded to 17 clinics, with data collected from 2,500 patients to date. This registry is one of the first of its kind being used for studying the health and treatment of patients with rare comp lex conditions. This year, a peer-reviewed paper was accepted for publication outlining the development of the registry.

- Completed a three-year research cooperative agreement to document the impact of Tourette Syndrome on individuals, families and communities, and publishing findings that showed increased health care needs and parent stress. Additionally, the Tourette Syndrome Education and Outreach program has connected evidence-based information on this condition to almost 100 programs representing more than 7,000 professionals and individuals.

Looking to the Future

NCBDDD's Division of Human Development and Disability is committed to better understanding and promoting optimal health and development of children with complex disabling conditions, hearing loss, or mental, emotional or behavioral conditions. We serve a critical role in identifying and communicating the needs of these populations.

We will continue to track and conduct research to learn more about prevention and intervention strategies that improve the health and long-term outcomes of children with these conditions. Our research will answer important questions about the health care needs and quality of life of children and youth to successfully transition them into adulthood.

Our work is changing the expectations for children living with these conditions. Public health holds the promise to support all children in reaching their full potential, so they can be actively engaged and highly productive. NCBDDD's Division of Human Development and Disability is positioned to help lead public health in fulfilling that promise.

Did You Know?

- Nearly 6,000 deaf and hard-of-hearing babies were identified in 2012 through Early Hearing Detection and Intervention (EHDI) programs.
- More than 15 million children are living in poverty. These children are at increased risk for poor health and developmental outcomes in childhood, adolescence and adulthood.
- Up to 1 in 5 children in the U.S. have a mental disorder. An estimated $247 billion is spent each year on childhood mental disorders.
- Early intervention treatment services can greatly improve a child's development.

Notable Scientific Publications

Wolraich, M. L., McKeown, R. E., Visser, S. N., Bard, D., Cuffe, S. P., Neas, B., Geryk, L. L., Doffing, M., Bottai, M., Abramowitz, A.J., Beck, L., Holbrook J. R., Danielson, M. The prevalence of ADHD: Its diagnosis and treatment in four school districts across two states. Journal of Attention Disorders. Published online 5 September 2012. DOI: 10.1177/1087054712453169.

Seltzer MM, Baker MW, Hong J, Maenner M, Greenberg J, Mandel D. Prevalence of CGG expansions of the FMR1 gene in a US population-based sample. American Journal of Medical Genetics Part B Neuropsychiatric Genetics; May 22, 2012 (Epub ahead of print)

Cyrus A, Quary S, Kable J, Kenneson A, Fernhoff P Clinic-based infant screening for Duchenne muscular dystrophy: a feasibility study. PLoS Currents Muscular Dystrophy; May 2, 2012

Mendell JR, Shilling CS, Leslie ND, Flanigan KM, al-Dahhak R, Gastier-Foster J, Kneile K, Dunn DM, Duval B, Aoyagi A, Hamil C, Mahmoud M, Roush K, Bird L, Rankin C., Street N. Evidence based path to newborn screening for Duchenne muscular dystrophy. Annals of

Neurology; January 12, 2012 (Epub ahead of print)

Notable Scientific Publications (continued)

Thibadeau JK, Ward EA, Soe MM, Liu T, Swanson M, Sawin KJ, Freeman KA, Castillo H, Rauen K, Schechter MS. Testing the feasibility of a National Spina Bifida Patient Registry. Birth Defects Research (Part A); Clinical and Molecular Teratology; November 2, 2012 (Epub ahead of print)

Soe MM, Swanson ME, Bolen JC, Thibadeau JK, Johnson N. Health risk behaviors among young adults with spina bifida. Developmental Medicine and Child Neurology; 2012 Nov;54(11):1057-64

Brustrom J, Thibadeau J, John L, Liesmann J, Rose S. Care coordination in the spina bifida clinic setting. Current Practice and Future Directions Journal of Pediatric Healthcare; 2012 Jan-Feb;26(1): 16-26.

Robinson LR, Bitsko RH, Schieve LA, Visser SN. Tourette syndrome, parenting aggravation, and the contribution of co-occurring conditions among a nationally representative sample. Disability and Health Journal. Published online 12 November 2012.

Bitsko RH, Danielson ML, King M, Visser SN, Scahill L, Perou R. Health care needs of children with Tourette syndrome. Journal of Child Neurology. Published online 8 November 2012.

To view the annual report online, visit:
www.cdc.gov/ncbddd/2012AnnualReport

For more information, visit:
www.cdc.gov/disabilities